The importance of a psychosocial focus in the treatment and management of type 1 diabetes in children

A comparison between Norway and Australia

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1 Abstract

Background
Type 1 Diabetes (T1D) is a chronic autoimmune disease in which a selective destruction of the insulin-producing β-cells in the pancreas results in insulin deficiency and hyperglycaemia, thus a dependance on exogenous insulin for survival. It is one of the most common chronic diseases in childhood and adolescence, and the incidence is increasing worldwide. Children and adolescents with T1D are at increased risk of developing psychiatric disorders and many report reduced quality of life. This emphasizes the importance of diabetes care by a highly qualified multidiciplinary team which includes mental health workers.
Aim
The aim of this study was to illustrate current research on psychosocial care for children and adolescents with T1D around the world, and to compare the diabetes care in Norway and Australia, mainly focusing on the organisation of diabetes teams and their attention towards the patient's mental health.
Methods
The thesis is divided in two parts. Part one is a literature review on T1D based on a non-systematic PubMed search, mainly focusing on mental health among children and adolescents with T1D. In part 2, the care for young patients with T1D at Oslo University Hospital (OUH) in Oslo, Norway, Royal Children´s Hospital (RCH) in Melbourne, Australia, Alice Springs Hospital (ASH) in Alice Springs, Australia and John Hunter Hospital (JHH) in Newcastle, Australia is presented. The discussed results are based on information gathered using a standardized electronic questionnaire on T1D, based on international guidelines for diabetes care, and personal experiences.
Results
At RCH and ASH, the most common treatment regime was twice-daily insulin injection unlike OUH and JHH where multi-injection therapy and insulin pump was most commonly used. Nevertheless, the average HbA1c was quite similar. All the presented hospitals used guidelines in their clinics. However, at ASH the recommended screening programs were not followed and no social worker nor psychologist was included in the diabetes care team. Even though the other three hospitals (OUH, RCH, JHH) had multidiciplinary diabetes care teams as advocated in The International Society for Paediatric and Adolescent Diabetes (ISPAD) guidelines, only one of these teams (OUH) include a psychologist. Comprehensive education and care was offered at all the hospitals, but the lack of organized reeducation and limited knowledge about their patients mental health was an important finding. Only OUH had organized reeducation for adolescents.
Discussion
At all the presented hospitals children and adolescents with T1D had access to recommended insulin preparations and treatment regimens, and the treatment and follow up was well organised. However, keeping in mind the high risk of developing mental health problems among these patients, an increased focus on psychosocial health should be implemented in the diabetes management. Furthermore, regular re-education might be helpful in understanding the disease and thus coping better. Coping is essential for good glycaemic control and for the patient's quality of life.
Conclusion
Achieving both metabolic and psychological stability in children and adolescents with T1D requires a multidisciplinary diabetes team that is equipped to provide physical, social and psychological support. A psychologist should be a compulsory part of the diabetes team and psychological interventions, such as screening programs for psychological issues, should be a part of the of diabetes care for young people.

2 Acknowledgements

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3 Abbreviations

ALO	Aboriginal Liaison Officer
APEG	Australian Paediatric Endocrine Guidelines
ASH	Alice Springs Hospital
BMI	Body Mass Index
BG	Blood Glucose
BGL	Blood glucose Level
BGM	Blood Glucose Monitoring
CBGM	Continuous Blood Glucose Monitoring
CSII	Continuous Subcutaneous Insulin Infusion
DAWN	Diabetes Attitudes, Wishes and Needs
DKA	Diabetic Ketoacidosis
DSME	Diabetes self-management education
HbA1c	Haemoglobin 1c
IDF	International Diabetes Federation
IDDM	Insulin-Dependant Diabetes Mellitus
ISPAD	The International Society for Paediatric and Adolescent Diabetes
JHH	John Hunter Hospital
MDI	Multiple Daily Injections
NCDR	Norwegian Childhood Diabetes Registry
NDR	National Diabetes Register (Australian)
NEDEC	New England Diabetes and Endocrinology Center
NPH	Neutral Protamine Hagedorn Insulin
NSW	New South Wales
NT	Northern Territory
OECD	Organisation for Economic Co-operation and Development
OUH	Oslo University Hospital
PYR	Person Years
QoL	Quality of Life
RCH	Royal Children's Hospital
SMBG	Self-Monitoring of Blood Glucose level
T1D	Type 1 Diabetes
T2D	Type 2 Diabetes
WE-CARE	Well-being and Satisfaction of CAREgivers of Children with Diabetes Questionnaire
WHO	World Health Organization

4 INTRODUCTION

4.1 Background

Diabetes mellitus is a group of metabolic diseases, characterized by chronic high levels of blood glucose resulting from defects in insulin production, insulin action or both. The majority of diabetes cases are either Type 1 diabetes (T1D) or Type 2 diabetes (T2D) [1]. T1D results from a cellular autoimmune destruction of the insulin-producing β-cells in the pancreas leading to insulin deficiency [2], while T2D is caused by a combination of resistance to insulin action and inadequate compensatory insulin secretory response [1].

There has been a worldwide increase in T1D during the last years [3]. According to WHO Multinational Project for Childhood Diabetes, T1D, also known as Insulin-dependant diabetes mellitus (IDDM), "is one of the most important chronic diseases of children worldwide" [4]. This emphasizes the importance of strategies to improve diagnosis, treatment, and prevention of complications among children and adolescents with the disease.

4.2 Aims

The aims of this student thesis were to compare the diabetes care for children and adolescents with T1D in Norway and Australia, two countries in very different parts of the world, mainly focusing on the organisation of diabetes teams and their focus on the patient's mental health. According to DAWN (Diabetes Attitudes, Wishes and Needs) Youth the support available today for children and their families is far from optimal, even in the most developed countries [5].

Furthermore, the thesis is a part of the larger study " Diabetes in children; a global comparative study". Several medical students are travelling to different countries around the world to study and compare the management of diabetes in children and adolescents. An important question raised in these comparisons is "Are the clinical practice consensus guidelines from the International Society of Paediatric and Adolescent Diabetes (ISPAD) adhered to?" The study is based on literature reviews and a standardized questionnaire.

4.3 Subject and methods

This thesis is divided into two parts. Part one is a literature review on T1D, mainly focusing on mental health among children and adolescents with diabetes. A non-systematic PubMed search was performed to gather information on T1D.

Part two is a clinical part consisting of results from a standardized semi-qualitative questionnaire (appendix 1), and personal experiences from hospitals in three different states of Australia and the capitol of Norway. The semi-qualitative questionnaire was designed to gather information about children with diabetes ≤ 15 years of age. The interview was split in two rounds. The first part of the questionnaire was designed to map T1D in children at a national or regional level. This was filled out based on information from the Internet and other available sources, and then talked through with a local informant. The second part of the questionnaire was designed to map T1D in children at the local hospital/treatment facility. Prior the interview the questionnaire was sent to the informant so that he or she could prepare himself/herself. The questionnaire contained multiple qualitative questions and was therefore tape-recorded.

In addition to Internet searching and personal interviews some answers to the questionnaires were collected via email from informants at the hospitals/treatment facilities.

The questionnaire at Oslo University hospital (OUH), in Norway, was completed a month prior the departure to Australia. Diabetes nurse, Siv Janne Kommernes, at the Children's department was interviewed. The outpatient clinic was also visited.

The interview at the Royal Children´s Hospital (RCH) in Melbourne in Victoria, Australia, took place in the third of a four-week clinical rotation. The clinical rotation consisted of daily work at the Department of Endocrinology and Diabetes, which included visiting in-patients with newly diagnosed T1D and admissions of other patients with known T1D regarding stabilization and re-education, visits to the Emergency Department where children with DKA were treated, diabetes-meetings with the consultants, fellow doctors, registrants and diabetes allied health team, out-patient diabetes clinics and diabetes education.

At Alice Springs Hospital (ASH) in Northern Territory, Australia, a diabetes educator and one of the paediatric consultants were interviewed. Although very few children with diabetes are treated here sufficient information was gathered to include the hospital in the study.

At John Hunter Hospital (JHH) in New South Wales, Australia, an endocrine paediatrician was interviewed and few outpatient clinics were visited.

The schemes did not contain personal sensitive information.

5 PART ONE – Literature review on type 1 diabetes in children and adolescents

5.1 Epidemiology

5.1.1 World

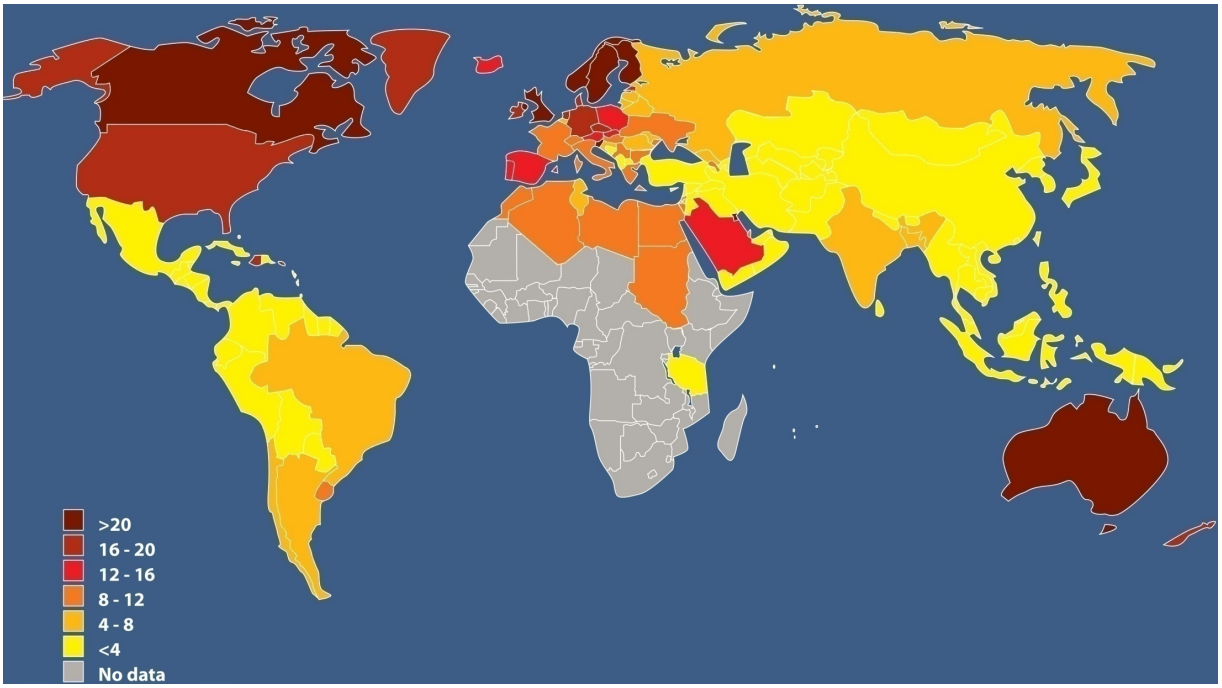
T1D is one of the most common endocrine and metabolic diseases among children and adolescents and the incidence, especially in children younger than 15 years, is increasing all over the world. The annual incidence increase in this age group is 3 % [3]. In 2010 the prevalence was 479 600 thousand between 0 and 14 years and the number of newly diagnosed children was 75 800 [3].

The incidence of T1D in children varies based upon geography [6], age [7-9] and family history [10]. In most populations around the world girls and boys are equally affected [11].

The increase in yearly incidence appears to be primarily in the younger age group. However, both in Norway and Australia the increase is largest in the age-group 10-14 years [12-14]. In a multicentre study from Europe where 17 European countries were included, an overall annual incidence rate increase of 3.9 % was revealed over a period of 15 years. The incidence rise was clearly highest in the youngest age group. Between 1989 and 2003 the incidence of T1D increased with 5,5% in children 0-4 years of age, 4.3% in the age group 5-9 years and 2.9 % in the age-group 10-14 years [15].

There is a substantial variation in incidence rates of T1D among children internationally. In worldwide research conducted by the International Diabetes Federation (IDF), Norway and Australia are both found to be amongst the top 10 countries in incidence rates for T1D in children 0-14 years old [16]. According to IDF, Finland had the highest incidence rate of 57.4 per 100 000 person-years (PYR) in 2010, followed by Sweden, Norway, the United Kingdom and Australia. Denmark, Canada and the USA are also high up on the list [16]. Fiji and Venezuela are among the countries with the lowest incidence rates (0.1 per 100 000 PYR) [16].

Table 1: The global incidence rate of Type 1 Diabetes aged 0-14 years in 2006.



Source: International Diabetes Federation. Available from: http://www.idf.org

5.1.2 Norway

Norway is amongst the countries with the highest incidence of T1D in the world and the rate is increasing [17]. In 1973 the incidence was 19 per 100 000 PYR among children between 0 and 14 years [18]. Between 1999 and 2003 the annual incidence was 28 per 100 000 PYR and in 2008 the incidence was increased to 33 per 100 000 PYR (Table 2a) and to 36 per 100 000 in 2009 [12].

In year 2009 361 new children, under the age of 18 years, were registered in the Norwegian National Diabetes Registry with a diagnosis of diabetes, 45% (163) girls. T1D was the most common diagnosis (98%). Among the total amount of registered patients, 335 (93%) were younger than 15 years at the time of diagnosis, and among these, 331 children had T1D (99%) [12]. Among the children with T1D that attended the yearly check-ups in 2009; 4% were younger than five years, 18% were between few and nine years and 45% between 10 and 14 years. The numbers are based on data from the National Childhood Diabetes Registry (NDCR) [12], a prospective population based registry for childhood diabetes in Norway.

Table 2a: Incidence and prevalence of type 1 diabetes in children < 15 years in Norway (year 2008)

	Norway
Incidence of T1D < 15 years	33 per 100 000 PYR
Prevalence of T1D < 15 years	Approx. 2700

Source: Annual report 2008, the Norwegian Childhood Diabetes Registry

5.1.3 Australia

Australia is also on the top-ten-list of countries with the highest incidence rates of T1D in children [14]. In the time period between 2000 and 2008 the average annual incidence of T1D among children aged 0-14 years in Australia was 22.8 per 100 000 PYR, with an increasing rate of 1.7% per year. The rate increased most in the period 2000-2004, with an average rate of 6%. Overall in the whole time period the annual rate was highest in the age group 10-14 years (in 2008), where the rate peaked at 30.9 per 100 000 PYR, with an average increase in rate of 2.3 %. Among children between 0 and four years and between five and nine years the incidence rate increased 0.7% and 2.2% in average, respectively. When comparing boys and girls, the incidence increase was significantly higher among boys then girls in the age groups 0-four years and 10-14 years. The overall incidence rate in 2008 was 23.9 (Table 2b) [14].

Table 2b: Incidence and prevalence of type 1 diabetes in children < 15 years in year 2008 in Australia.

	Australia
Incidence of T1D < 15 years	24 per 100 000 PYR
Prevalence of T1D < 15 years	Approx. 5000-6000

Source: Australian Institute of Health and Welfare 2010. Incidence of Type 1 diabetes in Australian children 2000–2008. Diabetes series no. 13. Cat. no. CVD 51. Canberra: AIHW, and the Diabetes manual at Royal Children´s Hospital.

Australia is a large country and the incidence rate of T1D varies greatly between the states with the lowest incidence seen in Northern Territory (NT) and the highest in Tasmania (Table 2c). The numbers are based on data from the Australian National Diabetes Register (NDR) [14], a prospective population based register for people with diabetes living in Australia.

Table 2c: Average incidence of Type 1 diabetes in children 0-14 years between 2000-2008 in the states of Australia

State in Australia	Incidence (per 100 000 PYR)
New South Wales	21.0
Victoria	24.0
Northern Territory	10.2
Queensland	23.2
Tasmania	28.3
Western Australia	22.9
Australian Capitol Territory	25.0
South Australia	25.9

Source: Australian Institute of Health and Welfare 2010. Incidence of Type 1 diabetes in Australian children 2000–2008. Diabetes series no. 13. Cat. no. CVD 51. Canberra: AIHW.

5.2 Aetiology and pathogenesis

T1D is characterized by a selective destruction of the insulin-secreting β-cells in the pancreas, leading to insulin deficiency [19]. It is a chronic autoimmune disease, which usually exists in a preclinical phase for a while. The classic manifestations such as hyperglycaemia, polyuria, polydipsia, weight loss, dehydration, electrolyte disturbances and ketoacidosis occur when most of the β-cells have been destroyed [2].

Serological markers of an autoimmune pathological process are present in 85-90% of individuals when fasting hyperglycaemia is detected [20]. In up to a third of the patients with T1D the autoimmune attack is not limited to the β-cells, and they develop additional autoimmune disorders, such as celiac disease, autoimmune thyroid disease (Hashimoto´s or Grave´s disease), Addisons´s disease, vitiligo, pernicious anemia and [21].

Genetic and environmental factors act together to precipitate the disease [22]. The genetic susceptibility is most importantly linked to the HLA region on chromosome 6p21 [23]. However, other non-HLA loci have been found to be associated with T1D. In the meta-analysis "*Genome-wide association study"* from 2009, they found that more than 40 distinct genomic locations provided evidence for association with T1D [24]. Nevertheless, only a relatively small proportion (<10%) of genetically susceptible individuals progress to a clinical

disease [25], implicating that additional exogenous factors are needed to trigger and drive β-cell destruction in the genetically predisposed subjects. Findings from two case-control studies have suggested that there might be an increased risk of developing T1D in genetic susceptible subjects that are introduced to cows milk and solid foods in early infancy [26, 27]. Enterovirus infections, especially Coxsackievirus B4 infections, are also among the suggested environmental risk factors potentially contributing to the development of T1D [28].

5.3 Diagnostic criteria

The diagnostic criteria for diabetes are based on blood glucose measurements and the presence or absence of symptoms. ISPAD have published the following criteria for diagnosing diabetes (Table 3) [29].

Table 3: The criteria for the diagnosis of diabetes mellitus from The International Society for Paediatric and Adolescent Diabetes (ISPAD).

Criteria for the diagnosis of diabetes mellitus
1. **Symptoms of diabetes plus casual plasma glucose concentration >/= 11.1 mmol/l (200 mg/dl). Casual is defined as any time of day without regard to time since last meal OR**
2. **Fasting plasma glucose >/= 7.0 mmol/l (126mg/dl). Fasting is defined as no caloric intake for at least 8 hrs OR**
3. **2-hour postload glucose >/= 11.1 mmol/l (200 mg/dl) during an OGTT. The test should be performed as described by WHO, using a glucose load containing the equivalent of 75 g anhydrous glucose dissolved in water or 1.75 g/kg body weight to a maximum of 75 g**

Source: ISPAD Clinical Practice Consensus Guidelines 2009: Definition, epidemiology and classification of dabetes in children and adolescents

5.4 Treatment

Children and adolescents with T1D are dependent on insulin treatment for survival [30]. The aim is to get an insulin replacement as close to normal physiology as possible, and to obtain optimal glycemic control. There are many insulin formulations available and many different insulin regimens.

5.4.1 Medication

Many formulations of insulin are available around the world (Table 4). A lot of countries use mainly insulin analogues in the treatment of T1D [30]. According to ISPAD, these analogues and human insulins are better than porcine or bovine insulin, because of low immunogenicity [30]. Devices such as insulin syringes, pen injector devices and continuous subcutaneous insulin infusion (CSII) or insulin pump are used to administer the insulin.

Table 4: Types of insulin preparations and suggested action profiles according to manufactors

INSULIN TYPE	Onset of action (h)	Peak of action (h)	Duration of action (h)
Rapid acting analogs (Novorapid, Humalog)	0.15-0.35	1-3	3-5
Regular/soluble /short acting (Actrapid)	0.5-1	2-4	5-8
Intermediate acting Semilente (pork)	1-2	4-10	8-16
***NPH (Protaphene)**	2-4	4-12	12-24
****IZP Lente type**	3-4	6-15	18-24
Basal long-acting analogs			
- Glargine (Lantus)	2-4	None	24
- Detemir (Levemir)	1-2	6-12	20-24
Long-acting			
- Ultralente Type	4-8	12-24	20-30

* NPH= Neutral Protamine Hagedorn Insulin. **IZP = insulin zinc suspension

Source: ISPAD Clinical Practice Consensus Guidelines 2009. Insulin treatment.

5.4.2 Insulin doses

The daily insulin doses depend on age, weight, stage of puberty, duration and phase of diabetes, state of injection sites, nutritional intake and distribution, exercise patterns, daily routine, results of blood glucose monitoring and intercurrent illness [30]. When taking all these factors into account it becomes clear that regular review and reassessment is required. In

the day-to-day life one should concentrate the three main factors; blood glucose, planned food intake and planned physical activity, when calculating the insulin doses.

5.4.3 Treatment regimens

There are several different insulin treatment regimens. The choice of regime depends on factors like the childs age, dietary patterns, exercise, duration of diabetes, school/work situation, patient/family/doctors preferences and costs. Most regimens include a proportion of short or rapid acting insulin and intermediate-acting insulin, long-acting or basal analog [31]. The following regimens are frequently used:

Twice-daily injection

The patient injects a mixture of short or rapid acting insulins and intermediate acting insulins twice daily. This is done before breakfast and the main evening meal.

Three-times daily

The patient injects a mixture of short or rapid and intermediate acting insulins before breakfast, rapid or regular insulin alone before evening meal and intermediate acting insulin before bed, or variations of this.

Multiinjection therapy

The patient injects insulin four or more times daily. 40-60% of the daily requirement should be basal insulin and the rest pre-prandial rapid-acting or regular insulin. The rapid-acting analogs are injected immediately before each meal (breakfast, lunch and main evening meal), regular insulin must be injected 20-30 minutes before meal and the intermediate-acting insulin or basal/long-acting analog is injected twice daily (morning and evening) or only at bedtime.

Insulin pump

The patient has an external pump that injects short-acting insulin in a combination of continuous injection (basal) and bolus-injections. This regime has the best possibility of imitating the physiological insulin profile [30].

5.4.4 Monitoring of glycaemic control

To obtain a blood glucose level (BGL) close to normal range (3.6-5.8mmol/l) monitoring of glycaemic control is essential, in addition to intensive insulin treatment. Monitoring of glycemic control includes daily monitoring of BGL at home as well as periodic monitoring of overall glycaemia. None of the above mentioned insulin regiments can be optimized without such monitoring [32].

Self-monitoring of blood glucose level (SMBG)

In the late 1970´s / early 1980´s, T1D patients started using instruments for self-monitoring of blood glucose levels (SMBG) [33, 34]. Since that introduction, SMBG has become a keystone in the daily management of blood glucose (BG) among patients with T1D. SMBG provides immediate documentation of hyperglycemia and hypoglycemia which allows implementation of strategies to optimally treat, as well as avoid, BGL out of range. According to the ISPAD guidelines SMBG should be measured four to six times daily [32].

Urine glucose

Unfortunately SMBG is an expensive tool and is not available for all patients with diabetes around the world. In countries where SMBG is not available, urine glucose is measured instead. Urinary glucose reflects glycemic levels over the preceding several hours [32].

Continuous glucose monitoring

Continuous blood glucose monitoring (CBGM) systems use a small sensor inserted under the skin to measure the glucose levels in the interstitial fluid. The sensors are replaced every 3-10 days and requires calibration two-three times daily. The user must check blood samples with a glucose meter in order to calibrate the device [32]. The CGMS provides detailed information on glucose fluctuations. Studies have shown that CBGM identify significantly more episodes of hypo- and hyperglycemias, and that usage of the system is associated with shorter duration of the hypoglycaemias [35, 36]. The system does not replace SMBG because approved devices are not as accurate and reliable as standard BG meters.

Urine and blood ketone testing

According to ISPAD guidelines, urine or blood ketone measurement should be monitored during episodes of uncontrolled hyperglycaemias, insulin deficiency, intercurrent illness and impending hyperglycaemia [32].

Glycated haemoglobin, HbA1c

HbA1c reflects the levels of glycaemia over the preceeding eight-twelve weeks, weighted towards the most recent four weeks [32]. Because the most recent glycation is reversible, the most recent week is not included. It has been shown to be the most useful measure to evaluate metabolic control. Furthermore it is an important measure in terms of its relationship with late micro- and macrovascular complications [37]. The target for HbA1c in all age groups is recommended by ISPAD to be < 7,5% [32].

5.4.5 Nutrition and carbohydrate counting

Nutritional management is an essential and complex part of diabetes care and education in children and adolescents. The aims should, according to the ISPAD guidelines, be to provide sufficient and appropriate energy intake and nutrients for optimal growth, development and good health, and to prevent acute and long-term complications. Furthermore, the aims are also to encourage lifelong eating habits, to achieve and maintain the best possible glycemic control and ideal body weight and to maintain and preserve quality of life [38]. Growth charts, BMI-measures and Tanner staging are important tools in monitoring the growth and development.

The primary nutrient that affects postprandial glycemic response is carbohydrates [39]. Carbohydrate counting is an useful tool in meal planning for patients with diabetes, because it allows the patients to have more flexibility in their food choices. Furthermore, studies have shown that the use of carbohydrate counting can reduce HbA1c [40].

5.4.6 Physical activity

Physical activity is another crucial component for children and adolescents with T1D considering both their physical and mental health. Exercise can improve lipoprotein profile, increase insulin sensitivity, lower blood pressure and improve cardiovascular fitess and quality of life in persons with T1D [41]. To achieve these positive effects, insulin and food intake must be carefully planned. During aerobic metabolism the uptake of glucose in the skeletal muscle increases in order to make energy for muscle contraction and hepatic

gluconeogenesis is suppressed. This leads to a decrease in blood glucose and thus an increased risk of hypoglycaemia [42]. Therefore adequate carbohydrate replacement, before, during and after excercise is very important to avoid severe hypoglycaemic events. Furthermore, a reduction in preprandial short-acting insulin doses is also essential when planning physical activity [42]. It can be very beneficial for the children to get accustomed to daily, regular excercise, because it will be easier to manage when it is a part of the daily routine [43]. Nevertheless, adjustments may still be necessary for sporadic extra physical activity. It is good practice to keep careful notes of the timing and intensity of the activity the child or adolescent performs, the carbohydrates taken and the blood glucose level before, during and after physical activity. This kind of recording is independant of the level of involvement in excercise the child or adolescent has adopted [43]. Careful advice considering management of diabetes and exercise to caregivers, coaches and teachers, including provision of written information, is important.

5.4.7 Record keeping/diabetes diary

Recording BGL´s and carbohydrate intake is not only important when performing physical activity. It is common practice, and recommended in the ISPAD guidelines, to record patterns of glycaemic control and adjustment to treatment every day in a diabetes diary, logbook or electronic memory device [32]. Several important factors should be included in the record book everyday.

According to ISPAD clinical consensus guidelines the record book should contain [32]:

- Blood glucose levels
- Insulin dosage
- Notes of special events affecting glycaemic control such as illness, parties, exercise, menses ect
- Hypoglycaemic episodes, including description of severity and potential alterations in the usual routine (this is important to help explain the cause of the event)
- Episodes of ketonuria/ketonemia

5.5 Ambulatory care/diabetes teams

Diabetes is primarily managed in outpatient/ambulatory setting. It is essential with a well-organized and regular ambulatory care for all children with diabetes for optimal blood glucose

control and to reduce the risks of acute and long-term complications, but also to optimize the children's quality of life. It is now accepted worldwide that an effective multidisciplinary team is crucial for providing good diabetes care to children and adolescents with T1D. One of the earliest reports of a multidisciplinary team approach was published by Laron et al in 1979 [44] . Several positive outcomes were revealed in their study where 262 children with juvenile diabetes and their parents were followed up on an ambulatory basis by a multidisciplinary team composed of a paediatric endocrinologist, nurse, dietician, psychologist and social worker. They found that the degree of glycaemic control increased, there were fewer complications and almost no need for hospitalization, the attitudes of the children, their families and teachers, were found to be considerably improved, so was the children's motivation to maintain the treatment regime and their self-concept. Furthermore, the conflicts in the families were reduced and the children's achievements at school and social adjustments were improved. Thus, they concluded that a multidisciplinary team approach in the treatment of T1D seem to be favourable. Although few similar studies have been conducted, international guidelines have implemented the use of multidisciplinary diabetes teams in the diabetes care for children and adolescents.

According to ISPAD clinical consensus guidelines from 2009 [45], the multidisciplinary diabetes care team for children and adolescents, should consist of:

- Paediatrician specializing in diabetes or endocrinology or a physician with a special interest in childhood and adolescent diabetes
- Diabetes nurse specialist or diabetes nurse educator
- Dietician or a nutritionist
- Paediatric social worker with training in childhood diabetes and chronic illness and/or psychologist trained in paediatrics and with knowledge of childhood diabetes and chronic illness

It is emphasized in the guidelines that the team should recognize the family and child as an integral part of the diabetes care team from the day of diagnosis.

In areas of low population density and where childhood diabetes rarely occurs, a multidisciplinary team is less likely available. In areas like these the care is likely to be

provided by a local physician/practitioner, but there should be access and advice easily available from diabetes care teams at regional centres [45].

The diabetes care team should provide expert advice and education for the children with diabetes and their families. Advices should also be given to schools and other venues where the children require care when away from home. At diagnosis the patient and his family must be taught survival skills. This includes an explanation of the diagnostic process, what has caused the symptoms, the consequences of the disease and the principles of insulin treatment. Practical skills (blood and/or urine testing and insulin injections) must be taught and different factors in the everyday life, such as food intake, exercise, stress and illness that influence on the blood glucose levels, and the thus insulin requirements, must be discussed. Furthermore it is crucial that the team educate the family on acute diabetes complications and the treatment of these. Initial learning should be reinforced by written guidelines and booklets, and the family must receive more thorough education and training when they comprehend and manage the basic principles of diabetes and it´s care [46].

Children with diabetes should be seen by a doctor/diabetes care team at least every third month. These care visits should include assessment of the child´s general health and well being, growth, glycemic control (HbA1c and analysis of home BG records) and treatment regiment. A more thorough annual review with greater attention to dietary assessment, educational updates and psychosocial needs and laboratory screening, including screening for co-morbidities and complications, is also recommended [45].

As children grow both their medical needs and their educational needs change [47]. It is a fine balance between giving the child too much and too little independence in the management of their diabetes. Therefore the diabetes team, the child and his or her family must continuously evaluate the child or adolescent´s needs.

Diabetes self-management education (DSME) is an important factor in reducing HbA1c in children with T1D [48]. In a study conducted by a multidisciplinary paediatric diabetes team at the Diabetic outpatient department of National Institute of Child Health, Karachi, in 2009, 60 children with a mean age of 10 years with T1D attended a diabetes self education program were they were educated regarding general information about diabetes, basic insulin therapy, planning for hypoglycemia, hyperglycemia, activity, travelling and basic nutritional

management. Among the 50 children who completed the trial there was a significant decrease in HbA1c after the DSME program with a mean pre- and post intervention HbA1c level of 9.67+/-0.65 and 8.49+/-0.53 respectively (p-value < 0.001) [48].

5.5.1 Diabetes care in pre-school and school

Children and adolescents spend approximately half of their waking hours at school. Keeping in mind that diabetes is a disease you have to handle at all hours through-out the day diabetes support and care at school is essential for the child´s physical and mental health. A child with diabetes need special considerations at school including access to and permition to perform blood glucose monitoring, free access to bathrooms and drinking water, ability to eat anywhere anytime and access to insulin administration. Teachers and other school personnel must have knowledge about diabetes and how to administer insulin and treat hypoglycaemias and hyperglycaemias. In a study from Florida children with diabetes received inadequate diabetes support according to parent reports [49]. They found that many of the children did not have written diabetes care plans, especially the Hispanic and black children. Furthermore, most children were not allowed to monitor their blood glucose nor inject insulin in class and most parents were worried about hypoglycemias and hyperglycemias in school. In another study where the children´s perceptions of diabetes support in school was examined, the results indicated that the children felt supported at school. However it was concluded that better flexibility among teachers and nurses and individualised care plans can improve their ability to manage their diabetes better in school [50].

5.6 Complications

The most common short term complications and comorbidities among children and adolescents with T1D include hypoglycaemia, hyperglycaemia and diabetic ketoacidosis (DKA) and psychiatric disorders [51]. Hypoglycaemia in pediatric patients with T1D, is usually defined as a blood glucose level below 3.6 mmol/l (<65 mg/dL) [52]. It results from a mismatch between insulin dose, food consumed, and recent exercise [52]. Mild hypoglycaemia is associated with adrenergic and neuroglycopenic symptoms, such as headaches and behavioral changes, and the most severe form is recognized by the precence of seizures or coma [53]. DKA is characterized by hyperglycaemia, acidosis and ketonuria and results from a combination of absolute or relative insulin deficiency and the effects of counter regulatory hormones such as catecholamines, glucagon, cortisol and growth hormone [54]. Psychiatric disorders are discussed in the next section (4.7).

The pathogenesis of long-term sequelae of T1D, including microvascular (nephropathy, neuropathy and retinopathy) and macrovascular complications (cardiovascular disease) begins in childhood [53]. The risk of these complications increases with poor glycaemic control and duration of diabetes. Although few children and adolescents have clinical evidence of micro- or macrovascular complications, at least in developed countries with well-organized diabetes care, subclinical findings of vascular disease can be detected. Early detection allows early interventions that may reverse the complications or at least delay further progression to clinical disease [53]. According to ISPAD guidelines screening programs for microalbuminuri, nephropathy, retinopathy and macrovascular disease should be part of the diabetes care for all children and adolescents with T1D [55].

5.7 Psychosocial issues

Diabetes is, as a chronic disease, difficult enough to handle for adults. It is even more challenging for children and young people as the diabetes interferes with their normal needs of childhood and adolescence. This includes the needs to succeed with schoolwork and sports and in social networks, and in the challenging transition to adulthood. The DAWN Youth initiative is a coordinated, international framework that works on the improvement of psychosocial support for children with diabetes internationally [5]. It is a global partnership initiative between IDF, ISPAD and Novo Nordisk A/S. The initiative has, through the largest study of its kind [5], recognized the great gap between children´s and adolescent´s needs for a psychosocial support to deal with their diabetes and what their healthcare system has to offer. One third of the patients in the study reported a feeling of "poor well-being" and about half of the patients reported a feeling of stress and anxiety due to their diabetes [56]. The initiative conclude with the fact that the support for children with diabetes and their families available today is far from optimal, even in the most developed countries. Ideally all these families should have access to a multidisciplinary team, consisting of a medical and psychosocial professional team.

In the ISPAD Consensus Guidelines 2000 it is emphasized that "Psychosocial factors are the most important influences affecting the care and management of diabetes" [57]. Furthermore in the guidelines from 2009 ISPAD recommend that social workers and psychologists should be a part of the interdisciplinary health care team, that expert help and support from mental health professionals should be given young persons or families with overt psychological problems and that the diabetes care team should receive training in the recognition,

identification and provision of information and counselling on psychological problems related to diabetes [58].

5.7.1 High rates of psychiatric disorders

Several studies have found that there is an increased incidence of psychiatric disorders among children and adolescents with T1D [59-61]. One prospective longitudinal study found a high risk of psychiatric disorders among adolescents with T1D [59]. In this study 37 % of the 41 adolescents included, met the DSMII criteria for a psychiatric disorder. This is 2-3 times higher than community levels of psychiatric disorders [59]. Furthermore, they found that there was an association between a history of poor controlled diabetes in the first 10 years after diagnosis and pre-existing behaviour problems. And this again was associated with increased risk of psychiatric disorders [59]. In another study from the Netherlands, 17.2% of the persons in a group of 233 youth between 9 and 19 years with T1D reported elevated depressive symptoms on the Child Depression Inventory. Of these, 28% received psychological care, 25 % wished to see a psychologist and 47% did not think it was necessary. Furthermore they found that only half of the youth talked to their doctor or nurse about their feelings. Their conclusion is that screening for depressive symptoms in the context of outpatient consultations can improve early detection and treatment of emotional problems [62].

5.7.2 Eating disorders among adolescents with type 1 diabetes

The prevalence of eating-disorders is significantly higher among adolescents with T1D than among non-diabetic teenagers [63, 64]. Potential risk factors for developing eating disorders that have been identified are among others; female gender [63], increased body weight, partially caused by insulin therapy, that lead to body dissatisfaction [64], difficulties with adapting to the hormonal and psychoemotional changes associated with puberty [65], a constant food preoccupation because of the diabetes [64, 66], problems with family relationships [63] and other psychiatric disorders, including depression and substance abuse [67].

An important complication in children and adolescents with diabetes and an eating disorder is poor glycaemic control and increased risk of frequent episodes of DKA [68]. Eating disorder is a severe disease; even more severe in adolescents with diabetes, and early diagnosis with screening programmes during the prepubertal period is important [69].

5.7.3 Fear of hypoglycemias

Several studies have shown that parents of children with diabetes show a significant fear of hypoglycaemias [70, 71], especially if the child has experienced a hypoglycaemic convulsion [72]. This fear may be a barrier for optimal glycaemic control, because a the parents might rather let the child run their blood glucose level higher than recommended to reduce the risk of development of hypoglycaemias.

In a field study from Virginia on children between 6 and 11 years and their parents, it was found that parents and children´s ability to recognize hypoglycaemias is a significant problem [73]. This again can be a risk factor for episodes of severe hypoglycaemia. More education and training for the children and their families to detect hypoglycaemias is needed.

5.7.4 Mental health screening

In a review article from 2007 the authors argue that mental health should be given equivalence to, or even precedence over, other complication screenings done in diabetes clinics [74]. They refer to several studies that have showed disturbingly high rates of psychological problems [59-61, 75], and that the problems are likely to persist into early adulthood [59, 76-79]. They conclude that complication-screening programs should include a mental health component from the time of diagnosis. Furthermore, they emphasise that considerations should be given to simplify screening of the rare micro vascular and autoimmune disorders to release resources for the more common psychiatric disorders [74]. In a randomized controlled trial from the Netherlands, periodic monitoring and discussion about health-related quality of life was proven to be appreciated by adolescents with T1D [80]. After a 12-month follow-up, patients in the intervention group reported improved self-esteem and mental health, significantly fewer behavioural problems and participated more in family activities. The adolescents in this study had relatively high levels of well-being prior the study, so further similar trials need to be conducted to see if improvements can be achieved in teenagers with lower levels of well being as well [80].

5.7.5 Treatment regimens, HbA1c and Quality of Life

In a large international multi-language study evaluating the relationship between metabolic control and Quality-of-Life (QoL) in adolescents with diabetes, they found that better metabolic control was associated with a better QoL [81]. They also suggested that since people with higher QoL may be better equipped both physically and psychologically to

handle the burdens of their diabetes management, a better QoL may also facilitate improved self-care and thus better metabolic control.

In another study conducted by the Hvideroe group, it was investigated whether differences in insulin treatment was associated with different outcomes in metabolic control among adolescent patients with T1D [82]. No improvement in HbA1c was observed even among the adolescent who changed from twice daily to multiple injections, indicating that insulin treatment is only one aspect of the diabetes treatment, and other factors such as attitudes of the treatment team, self care behavior, education models and patient satisfaction may be more directly related to the outcomes than the insulin regiments.

A systematic review and meta-analysis of randomised controlled trials on *"psychosocial outcomes following education, self-management and psychological interventions in diabetes mellitus",* concluded that psychological treatment can slightly improve glycaemic control in children and adolescents with diabetes [83]

5.7.6 Parental burnout

When a child is diagnosed with diabetes a whole family is affected. Some families cope very well others do not cope at all. In Sweden 252 parents of children with T1D answered a self-report questionnaire that assessed symptoms of parental burnout and background factors [84]. They found that parental burnout was associated with low social support, lack of leisure time, financial concerns and a perception that the child´s disease affects everyday life [84]. There was no association between sociodemographic or medical factors and burnout. The Quality of Life study conducted by the Hvideroe group showed an impact of family structure and ethnicity on QoL [81].

It is important to recognize the parent's attitudes and concerns associated with their child´s diabetes, but also other factors in the everyday life that might make things extra challenging. Several studies have shown that parents of children with diabetes experience greater levels of stress than parents of healthy children [85, 86]

A diabetes-specific questionnaire on parent´s quality of life and satisfaction with their child´s diabetes treatment, the Well-being and Satisfaction of CAREgivers of Children with Diabetes Questionnaire (WE-CARE) was developed in the United States in 2007 [87]. A psychometric

validation was conducted (parents of 116 children with T1D aged 6-11 years were included) and the data suggested that WE-CARE provides a reliable and valid measure of parent´s well-being and satisfaction with the treatment related to their child with diabetes [87].

The parent's perceptions of the child's treatment will necessarily have significant impact on their own well-being, and also the child´s well-being. Furthermore this might affect the child´s compliance, glycaemic control and quality of life. In a recent study from the USA where parents of children with T1D received either group-based educational training, or group-based coping skills training the findings suggested that group-based intervention in general may improve the parents coping and their quality of life [88].

5.8 Guidelines

5.8.1 ISPAD guidelines

ISPAD work to promote "optimal health, social welfare and quality of life for all children with diabetes around the world". The new and enriched edition of the Clinical Practice Consensus Guidelines from 2009 is based on a wide consensus of clinical practice. The guidelines have been modified by experts in different specialities around the world, debated at annual ISPAD meetings and reviewed by the ISPAD members [89], and are now used in many countries in the daily care of patients with diabetes.

In Norway the ISPAD guidelines are followed.

5.8.2 Australian guidelines

In Australia the management of children with diabetes is based on the Australian Clinical Practical Guidelines: T1D in Children and Adolescents prepared by the Australasian Paediatric Endocrine Group for the Department of Health and Aging. The guidelines were published in 1996 and updated with an evidence-based approach by a national multidisciplinary writing committee, and approved in 2005 [90]. When developing the latter version, other guidelines, position papers and technical reports regarding the management of T1D in children and adolescents were sought from the World Health Organization (WHO), International Diabetes Federation (IDF), American Diabetes Association (ADA), National Health and Medical Research Council (NHMRC), Australian Paediatric Endocrine Group

(APEG), ISPAD, National Institute of Clinical Excellence (NICE) guideline on T1D and more.

Related to the subjects of this thesis there are no major differences between the ISPAD and the APEG guidelines, thus including a thorough comparison in this paper was not found to be necessary.

5.9 Diabetes Databases

Norway and Australia both have prospective, population based national diabetes registers.

In Norway there is a particular register for diabetes in children; The Norwegian Childhood Diabetes Registry (NCDR). The register is based on The Norwegian Study Group of Childhood Diabetes, which is a network of all paediatricians treating diabetes in Norway. The patients and their parents have to consent to be included in the registry. NCDR was established in 2006. It includes data on childhood diabetes incidence since 1989 and annual data on the quality of care since 2000. In addition the incidence of complications is documented [12]. All data is valid and ethically improved.

In Australia the database is called The National Diabetes Register (NDR). It collects information about people who use insulin in the treatment of their diabetes. Persons with T1D, T2D and gestational diabetes who started to use insulin after the 1st of January 1999 and have consented to be a part of the database are included. The Register obtains information from two main data sources, 1) the National Diabetes Service Scheme, administered by Diabetes Australia and from 2) the Australasian Paediatric Endocrine Group (APEG) state based register. The latter register collects information about persons with diabetes under the age of 15. All reports on incidence and information on epidemiological and clinical studies in NDR are valid and ethically improved [91].

5.10 National Diabetes Organisations

In Norway there is a national diabetes organisation called *Diabetesforbundet*. It is divided into 137 smaller local departments and has a total of more than 40 000 members [92]. A membership includes access to magazines on diabetes, courses, educational programs, social

happenings, summer camps, reduced prizes on diabetes products, advocacy help and online resources including a webpage for young people with diabetes.

Diabetes Australia is Australia's National Diabetes organisation [93]. The organisation is divided into departments in each state; Diabetes Australia-Victoria, Diabetes Australia-New South Wales, Healthy Living Northern Territory etc. A membership in Diabetes Australia includes access to updated information and magazines on diabetes (special magazines for children and teenagers), courses, educational programs, supermarket tours, telephone support (Diabetes Info Line), Advocacy Officer, reduced prizes on diabetes products, cheaper travels, health insurance and some diabetes services, camps for young people, support groups and online resources.

6 PART TWO – The clinical part

6.1 Results and personal experiences

This part contains results from a comparison on the management of T1D in children and adolecents at hospitals in three states in Australia and the capitol of Norway. My personal experiences from participation in outpatient appointments, educations sessions etc. is included here.

6.1.1 Presentation of the four visited hospitals

6.1.1.1 Oslo

I visited the children´s clinic at Oslo University Hospital (OUH) in 2009 prior my departure to Australia. The local informants helping me to fill out the questionnaire were Diabetes Nurse Siv Janne Kummernes and Senior Consultant Torild Skrivarhaug, MD.

Oslo University Hospital, Oslo, Norway
OUH is placed in Oslo, the capitol of Norway. The paediatric department at OUH, including a 22-bed children´s ward and an outpatient clinic, is the largest for children with diabetes in Norway. It covers a considerable area in the southeast of Norway; Oslo, Asker and Bærum. More than 300 children with diabetes are followed up here (Table 7).

6.1.1.2 Melbourne

The Royal Children´s hospital (RCH) [94], in Melbourne was visited in October and November 2009. During my clinical rotation here I participated in the daily work with children and adolescents with T1D. Diabetes Educator Andrew Boucher, the Allied Health Team (diabetes team) and Professor Fergus Cameron were interviewed.

The Royal Children´s Hospital (RCH) in Melbourne, Victoria, Australia
The Royal Children´s Hospital is placed in Melbourne, the state capitol of Victoria. It is the major specialist paediatric hospital in Victoria and is internationally recognized as a leading centre of paediatric treatment, teaching and research. RCH care for children from Victoria, Tasmania, southern New South Wales and other states around Australia and overseas. Admissions for diabetes go to the children´s medical ward (32/33 beds) and the adolescent ward (20/22 beds). Approximately 1500 children with Type 1 Diabetes are followed up at RCH, in addition 200 children outreach in regional centres (Table 7).

6.1.1.3 Alice Springs

After my stay at RCH in Melbourne I went to Alice Springs Hospital [95-97]), placed in the centre of Australia. Local informants here were Diabetes Educator Glynis Dent and Dr. Rose Fahy

Alice Springs Hospital, Alice Springs. Northern Territory, Australia.
ASH is a 189-bed specialist teaching hospital situated in the Red Centre of Australia. The population (55 000 people) in the middle of Australia is dispersed over 1.6 million square kilometres. Approximately 60 % of the patients admitted to ASH are aboriginal. Statistics indicate that Aboriginal patients remain in hospital, on average, longer than non-Aboriginal patients and occupy approximately 80% of occupied bed days at any time. English is often a second, third or fourth language among the aboriginal patients and team of Aboriginal Liaison Officers assist the patient management by providing interpretation services and social, emotional and cultural support.
The hospital has a children´s ward with 40 beds and an out-patient clinic. 8 children with T1D are followed up at ASH (Table 7).

6.1.1.4 Newcastle

John Hunter Hospital (JHH) [98], in Newcastle, New South Wales, Australia, was visited in 2010. The local informant here was Professor Patricia Crock.

John Hunter Hospital, Newcastle. New South Wales, Australia
John Hunter Hospital is placed in Newcastle, NSW´s second largest city after Sydney. The hospital houses one of the three designated children´s hospitals in NSW, providing health care for children up to 18 years of age from the Hunter New England Health region and other parts of northern NSW. There are a total of 110 beds in the paediatric part of JHH. This includes 41 beds in the Neonatal Intensive Care Unit, 14 beds in Day-Stay, 19 beds in the surgical ward, 24 beds in the children´s medical ward and 12 beds in the adolescent ward. Approximately 360 children and adolescents are followed up at JHH (Table 7). This number includes teenagers between 15 and 18 years.

6.1.2 Hospital admissions

Type 1 diabetes

In 2007, 27 children younger than 18 years of age were admitted to OUH with a new diagnosis of T1D. In 2009 the number of newly diagnosed was 35. At RCH the annual number of newly diagnosed children in the same age group is 130-150. Another 50-60 children with known T1D, are each year admitted for stabilisation. The number of T1D admissions is a lot smaller at ASH, which is placed in the Australian state with the lowest incidence rate of T1D among young people (Table 2c). In year 2000 only one child was diagnosed with T1D at this hospital. The year after ASH had 11 T1D admissions. Five of these admissions were the same child. In 2008 four children with T1D were admitted, where of two were newly diagnosed and two were readmissions [99]. Approximately 220 children with T1D are admitted to JHH annually. The admissions include children with newly diagnosed diabetes, readmissions for stabilization and pump starters (Table 5).

Table 5: Annual hospital admissions among children with type 1 diabetes < 15 years at one hospital in Oslo, Norway and hospitals in three different states in Australia. The numbers (approximates) include newly diagnosed, readmissions and pump starters.

	Oslo University Hospital, Oslo	**Royal Children´s Hospital, Melbourne, Victoria**	**Alice Springs Hospital, Alice Springs, Northern Territory**	**John Hunter Hospital, Newcastle, New South Wales**
Children with T1D < 18 years admitted to the hospitals annually (2007-08)	27-35 newly diagnosed	130-150 newly diagnosed and another 50-60 admissions for stabilisation	Depends; between 1 and 11 admissions between 1999 and 2008	Approx. 220
Children followed up at the hospitals (per 2009)	303	1500 *	8	363

- ** The endocrinologists at RCH care for an additional 200 patients in regional centres (Outreach)*

Type 2 Diabetes

Although once considered as a disease of adults, the prevalence of Type 2 Diabetes (T2D) is also increasing among children and adolescents worldwide [100]. All the hospitals I have visited also care for a few adolescents with T2D. During my stay at RCH I met two teenage girls (11 and 13 years old) with T2D. They both had extremely bad compliance with a very high BMI and HbA1c. What characterized these two young girls was inactivity and unhealthy food intake. Even during their stay at the hospital they ordered fast food. The girls where admitted for several days for re-education and stabilization because of their high HbA1c levels. During my 6 weeks at the children´s ward at ASH I did not meet any children with T1D. However, I met a teenage girl admitted for stabilization of her badly controlled T2D. Her characteristics were similar to the girls with T2D I met at RCH.

6.1.3 Time of diagnosis

All the presented hospitals adhere to national guidelines based on the ISPAD guidelines (Table 3) for the diagnosis of T1D. The diagnosis of T1D is always made/confirmed by specialized health services. This rule applies to all the visited hospitals (Table 6).

Oslo University Hospital

At OUH the patients are usually sent from their general practitioner (GP) who strongly suspect the diagnosis of diabetes. When diabetes is confirmed, the child is admitted (always) and the initial diabetes treatment and education is commenced. The average length of stay at diabetes onset is 11 days (Table 6). It varies between 6 and 14 days, depending on the presentation, the child´s age, the family etc. A diabetes doctor and ward nurses are responsible for the initial treatment. Within the first days the child and family meet the whole diabetes team, consisting of diabetes nurses, a dietician, a social worker and a psychologist. Interpreters are available.

Royal Children´s Hospital

Many children are diagnosed with diabetes in general practice and then referred to RCH, where the diagnosis must be confirmed. Most often the child is then admitted for the initial treatment and education. A paediatrician and the diabetes team are responsible for the initial treatment. The average time of stay at the hospital at diabetes onset is 4 days (Table 6). However, some patients are not admitted. In the Australian guidelines it is emphasized that in appropriately chosen patients there are “no disadvantages of ambulatory management compared

to inpatient management of children and adolescents with newly diagnosed T1D" [90]. Depending on the child´s age, the clinical status and how the child and family copes with the new diagnosis, a decision is made by the diabetes team and the family whether admission or out-patient treatment is the best choice in the acute phase. In some cases the diabetes team visits the family at their home place to inject insulin and to educate the family the first few days. All children under the age of 2 years must be admitted. This is also the case if the family lives more than 30 km from RCH or if they live closer but do not have a car. Furthermore, if the family needs an interpreter admission is necessary.

Alice Springs Hospital

In the Red Centre of Australia diabetes is very often randomly diagnosed in a child that comes to the emergency department with a viral infection, for example a urinary tract infection. The blood glucose is usually very high and the child is ketotic at investigations. When the family is asked specific about polyuria and polydipsia they confirm that this has been a problem the last days or weeks prior hospitalization. This might implicate that the people living in Central Australia are not well enough informed about symptoms of T1D. Lower incidence of T1D in NT compared to other parts of Australia, language problems among the aboriginal population and the fact that the population is dispersed over a large area, could be some of the reasons for this. A diagnosis of diabetes always leads to admission. A paediatrician is responsible for the initial treatment. The average length of stay is between 3 and 5 days (Table 6), depending on the child´s age, family situation etc. A lot of families stay up to 10 days at the children´s ward. If the family need an interpreter during their stay, this can be organized.

John Hunter Hospital

Most often children are diagnosed with T1D in general practice and then referred to JHH for confirmation of the diagnosis, initial treatment and education. A paediatrician and diabetes educators from the specialised diabetes team are responsible for this. The child is then admitted (always). The average length of stay at diagnosis is four-five days (Table 6). Interpreters are always available.

6.1.4 Diabetic ketoacidosis (DKA) at diagnosis

The ISPAD criterias for DKA are adhered to at all the visited hospitals (Table 6).

The ISPAD diagnostic biochemical criteria for DKA [101]:

- Hyperglycemia (blood glucose > 11 mmol/L [200mg/dL])
- Venous pH < 7.3 or bicarbonate < 15 mmol/L
- Ketonemia and ketonuria

Mild DKA: venous pH < 7.3 or bicarbonate < 15 mmol/L
Moderate DKA: pH < 7.2, bicarbonate < 10 mmol/L
Severe DKA: pH < 7.1, bicarbonate < 5 mmol/L

Approximately 25% of the children admitted to OUH with a new diagnosis of T1D have DKA at the time of diagnosis. Almost the same amount of children, approximately 28%, has DKA at the time of diagnosis at RCH. At ASH and JHH the number is unknown (Table 6).

Table 6: At diabetes onset the diagnostic criteria for type 1 diabetes used at one hospital in Oslo, Norway and three hospitals in three different states in Australia

	Oslo University Hospital, Oslo	**Royal Children´s Hospital, Melbourne, Victoria**	**Alice Springs Hospital, Alice Springs, Northern Territory**	**John Hunter Hospital, Newcastle, New South Wales**
Diagnostic criteria for T1D	National guidelines based on ISPAD	APEG and ISPAD	APEG and ISPAD	APEG and ISPAD
Confirmation of diagnosis	Specialized health service	Specialized health service	Specialized health service	Specialized health service
Number of children with DKA at time of diagnosis	25%	28%	?	?
Diagnostic criteria for DKA	ISPAD criteria	ISPAD criteria	ISPAD criteria	ISPAD criteria

	Oslo University Hospital, Oslo	Royal Children´s Hospital, Melbourne, Victoria	Alice Springs Hospital, Alice Springs, Northern Territory	John Hunter Hospital, Newcastle, New South Wales
Admission to the hospital when newly diagnosed	Yes	Yes	Yes	Yes
Average time of stay at the hospital	11 days	4 days	6-7 days	4-5 days

6.1.5 Adolescent ward

There is no adolescent ward at OUH, ASH or JHH, and young people with diabetes are therefore usually followed up at the Children´s Department until they turn 18 years old.
At RCH, on the other hand, there is an adolescent ward. Adolescents diagnosed with T1D are admitted to this ward, but there are no special adolescent endocrinologists there. The paediatricians and the diabetes allied health team at the hospital, consequently manage both children and adolescents with diabetes. However, adolescents and young adults can be followed up at special adolescent clinics outside the hospitals in the intermediate period between paediatric management and adult medicine management.

6.1.6 Treatment regimens

Oslo University Hospital

In Norway the most common treatment regimens for children of all ages are insulin pump and multi-injection therapy. The preferred regimens for toddlers and youngsters in Norway are insulin pump therapy. At OUH toddlers and young children are routinely started on insulin pump treatment when diagnosed with T1D. Older children and teenagers are either on the pump (~ 60%) or on multi-injection therapy (~ 40%). Twice-daily insulin treatment is hardly ever used at OUH (Table 7).

Royal Children´s Hospital

RCH think somewhat differently when it comes to treatment regimens. Most toddlers and young children followed up here are treated with twice daily insulin injections (50%). The injections are usually given before breakfast and dinner, and consist of a combination of short

or rapid-acting insulin and intermediate-acting insulin. The rationale behind this choice of treatment for the youngest children is to avoid focus on diabetes when they are at pre-school or school. Most schools do not have school nurses to help with insulin administration making it difficult for the youngsters to take their injections. Furthermore, a young child has a quite regular schedule when it comes to meals and amount of activity. Therefore the diabetes team at RCH believe that administration of insulin twice daily combined with a planned and balanced diet is optimal for the youngest children. However, when they reach their teenage years and their blood glucose levels become more difficult to control with this regime, multi-injection therapy is commenced. At RCH approximately 20% of the total patient population are on multi-injection therapy and 30% are on the insulin pump (Table 7). A lot of questions are raised when insulin pump is discussed at RCH. One important issue is "Who is responsible to control the pump at school/playgroup?" Another issue is cost. It is a very expensive regime in Australia, and almost impossible for a family to afford it without private health insurance. This takes time. The child needs to have the private health insurance one year prior applying for the pump.

Alice Springs Hospital

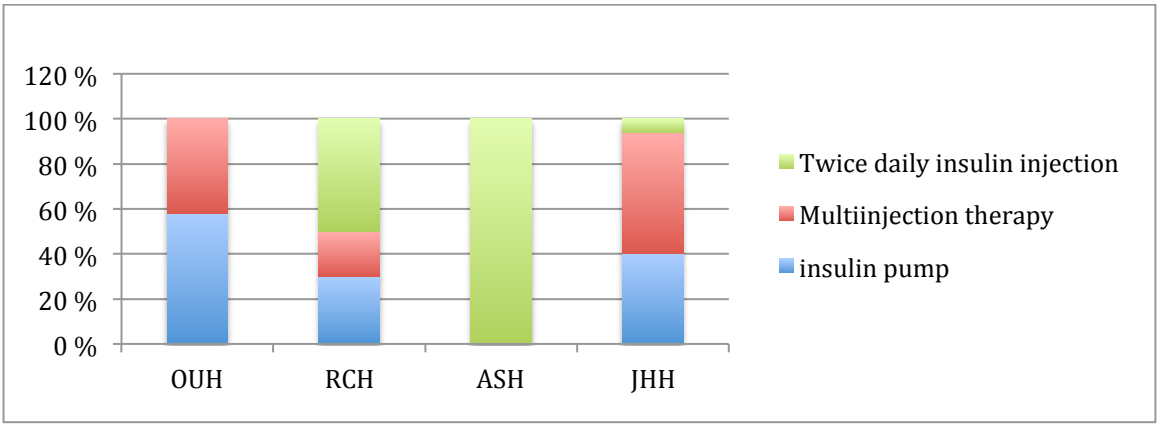
All children are started on twice-daily injections at ASH, which is the only treatment regime used at this hospital (Table 7).

John Hunter Hospital

Since 2004 the endocrinologists at JHH have recommended their patients to use multi-injection therapy or insulin pump. For patients using multiple daily injections (MDI) they have developed a Bolus Card Calculator, called ezy-BICC, to help determine the amount of rapid-acting insulin to inject before meals. The patients use their current blood glucose level (BGL) and their planned intake of carbohydrate exchanges to read the insulin dose from the individualized table on the ezy-BICC. The values in the table depend on the following variables: carbohydrate ratio, correction ratio, target BGL, a low BGL and carbohydrate discounted in the calculation if the BGL falls below this value. In a study between year 2000 and 2006 comparing young patients on MDI using ezy-BICC, with young patients on mixed insulin and insulin pump, they found that the patients on ezy-BICC and on insulin pump achieved lower HbA1c than those on mixed insulin[102]. Very young patients achieved excellent HbA1c using the pump, but for 12-20 years olds the ezy-BICC resulted in lower HbA1c than the pump for a lower cost [102]. The ezy-BICC system is inexpensive and

convenient and allows patients to vary meal size. Per December 2010, 52% are on this regime, 38% on insulin pump, 3.7% on fix dose MDI and 6% on conventional (two or three times daily) insulin treatment (Table 7).

Table 7: Proportion of children with type 1 diabetes on different treatment regiments at Oslo University Hospital (OUH) in Oslo, Norway* and Royal Children´s Hospital (RCH) in Melbourne, Australia, Alice Springs Hospital (ASH) in Alice Springs, Australia and John Hunter Hospital (JHH) in Newcastle, Australia (approximates). Numbers are from 2008.



**The only hospital in Oslo that treat children with diabetes*

6.1.7 Carbohydrate counting

At all the four hospitals carbohydrate counting is used systematically when calculating the insulin boluses in relation to food. Many children in Norway and Australia have smart-telephones, and an application for carb-counting is available on the Internet to download.

6.1.8 Treatment goals and average HbA1c

The treatment goal at OUH, RCH and ASH is HbA1c less than 7,5% (Table 8). Few children reach this goal. At OUH approximately 24 % of the young patients with T1D have HbA1c less than 7,5%. At RCH approx. 30% reach the goal. The number is unknown at ASH, but at least 50% do not reach the goal. At JHH the treatment goal is slightly stricter. They target all their T1D children to have HbA1c < 7% (Table 8). The percentage of children who reach this goal is unknown. IN 2008, the average HbA1c in Norway and Australia is 8,6% and 8,4% respectively.

Table 8: The treatment goals (HbA1c) and average HbA1c in 2008 among children and adolescents with Type 1 Diabetes in Norway and Australia.

	NORWAY*	AUSTRALIA**	OUS, Oslo, Norway	RCH, Victoria	ASH, Northern Territory	JHH, New South Wales
Treatment goal- HbA1c	< 7.5%	< 7.5%	< 7,5 %	< 7.5%	< 7.5%	< 7 %
Average HbA1c	8.6%	8.4%	8,7%	8.1%	Unknown	Unknown

The numbers are collected from 2008 and are collected from the Norwegian Childhood Diabetes Registry and the APEG Register in Australia**.*

6.1.9 Multidisciplinary team

Oslo University Hospital

In the Norwegian National strategy for diabetes from 2006-2010 the establishment and strengthening of diabetes teams in the management of persons with diabetes was emphasized. [103]. At paediatric departments in Norway the multidisciplinary teams should consist of one fulltime diabetes nurse/educator per 100 patients at the outpatient clinic, one or two nurses with knowledge about diabetes at the ward, one or two consultant doctors with interest in diabetes or paediatric endocrinologists, one doctor in learning/registrar, one dietician in a minimum of 50% position, one social worker in a minimum of 20% position and one psychologist in a minimum of 40% position. In addition a bioengineer and a pharmacist should be attached to the team as consultants [104]. OUH have managed to compose such a multidisciplinary team responsible for the management of children with T1D. The team consists of doctors with a special interest in children with diabetes, diabetes nurses, a social worker in a part time position (40%), a dietician in a part time position (40%), and a psychologist in a part time position (50%) (Table 9).

Royal Children´s Hospital

At RCH in Melbourne the diabetes team is also highly qualified, consisting of paediatric endocrinologists (three consultants and four registrars), five diabetes nurse educators, two dieticians working part-time in the team (75%) and two social workers (Table 9). Although

this is a multidisciplinary team, the lack of a psychiatrist or a psychologist is an important issue. The team at RCH have been working towards the engagement of a mental health worker on a permanent basis, but it is a matter of financial constraints. Today psychologists are involved only if the children have psychological issues in addition to the common mental health issues that are raised when having a chronic illness like diabetes.

Alice Springs Hospital

Because there are very few children and adolescents with diabetes at ASH, the hospital does not have a multidisciplinary team like RCH or OUH. Nevertheless, whenever there is a child who is admitted with diabetes, and when children and adolescents visit the outpatient clinic for their check-ups, the paediatricians, the diabetes educator and a dietician at the hospital work together as a functional team (Table 9). If the family is aboriginal, an aboriginal liaison officer (ALO) is also included. The ALO can provide emotional, social and cultural support to the patients and their families, liaison services and information about hospital services and the linkage between the hospital and the indigenous community resources. A diabetes educator from Healthy Living NT (Diabetes Australia) also engages in the management of children diagnosed with T1D at ASH.

John Hunter Hospital

At JHH a multidisciplinary team, like the ones at OUH and RCH, is responsible for the management of children with T1D. The team consist of three paediatric endocrinologist, three credential diabetes educators, one social worker and one dietician in a 70 % employment/position (Table 9). Each child has one particular doctor. The need for a psychologist on the team is recognized, but it is, as for RCH, a cost issue at the moment.

The diabetes teams available for children and adolescents with T1D in Norway and Australia also care for the children wit T2D. No separate teams for young patients with T2D are available.

Table 9: Members of the diabetes teams at one hospital in Oslo, Norway and three hospitals in three different states in Australia

	Oslo University Hospital, Oslo	Royal Children´s Hospital, Melbourne, Victoria	Alice Springs Hospital, Alice Springs, Northern Territory	John Hunter Hospital, Newcastle, New South Wales
Doctor	4	7*	1 (2)	3
Nurse/credential diabetes educator	2.3	5	1	3
Dietician	0.4	1.5	1	0.7
Social worker	0.4	2	0**	1
Psychologist	0.5	0***	0***	0***
Other			1****	

- ** 3 Consultants and 4 Registrars*
- *** only if there are family issues*
- ****Available on request*
- ***** Aboriginal Liaison Officer and GP*

6.1.10 Follow up and Management – Diabetes Clinics

Oslo University Hospital

OUH aim to give every child with diabetes a primary doctor. The child is seen by this doctor every third month in the paediatric outpatient clinic (Table 10). Sometimes consultations every six weeks is necessary, and extra consultations with a diabetes nurse are often offered in addition to the doctor´s appointments. At every consultation the doctor and the child/family study the child´s diabetes diary and talk about concerns, what´s going good and what´s going not so good. The child´s HbA1c is measured, growth and development is monitored and an examination to look for fatty lumps (lipohypertrophy) is always included. Most children attend their appointments. In addition to the check-ups, the child and family can call the diabetes team anytime for advice and to arrange extra consultations.

Royal Children´s Hospital

At RCH in Melbourne all the consultations for children with T1D are organised in special diabetes clinics. The consultations take place twice a week; Wednesday and Thursday afternoons in the outpatient clinic. The clinics run from three - five pm, and are exclusively

for children and adolescents with diabetes. The children with and their families are seen every third month on these days (Table 10). On arrival, approximately 30 minutes before their doctor's appointment, the children are measured and weighed, and a blood sample is taken. By the time they are seen by their doctor, the HbA1c result is ready and can be discussed in the consultation. In the meantime, while waiting for their appointment, the diabetes nurse educators and dieticians from the diabetes team, talk to the families. In this way the families can easily book appointments if the family, child or the educators or dieticians find it necessary with additional education sessions or nutritional advice.

At every consultation, the doctor and the child/family study the child´s diabetes diary and talk about concerns, what´s going good and what´s going not so good. The child's height and weight is plotted on a growth chart, the HbA1c is discussed and an examination to look for fatty lumps (lipohypertrophy) is performed. Most children attend their appointments.

The members of the diabetes teams are always available for telephone consultations and problem-solving assistance.

Alice Springs Hospital

Although there are few children with diabetes who are followed up at ASH, the paediatric team try their best to adhere to the ISPAD and the APEG guidelines. A general, a paediatrician at ASH is responsible for the treatment of the child. Sometimes an endocrinologist (not a paediatric endocrinologist) is involved too. The child and family visit the hospital for the doctor's check-ups every third or six months (Table 10). They all have their consultant doctor´s phone number and can contact him or her if they need advice or support. Furthermore, a community diabetes educator from Healthy Living NT (Diabetes Australia in NT) is also involved in the management of children with diabetes in the area around Alice Springs and in the community. Only 50-75% of T1D at patients attend their appointments at ASH. The compliance is very low amongst aboriginals, but also amongst caucasian teenagers.

John Hunter Hospital

At JHH the children are followed up by their endocrinologist and the diabetes team every third month, or every second month for toddlers (Table 10). At each consultation the doctor and the child/family study the child´s diabetes diary and talk about concerns, what´s going

good and what´s going not so good. Their HbA1c, height, weight and abdominal circumference is measured. The BMI is noted and the child is examined to look for fatty lumps (lipohypertrophy). Most children attend their appointments.

If a child has HbA1c > 10% at two successive check-ups, he or she is admitted for stabilization immediately. At one outpatient clinic I observed that 2 children with HbA1c of 12% and 10,4% had to be admitted for stabilization.

Table 10: Frequency of diabetes check-ups at one hospital in Oslo, Norway and three hospitals in three different states in Australia

	Oslo University Hospital, Oslo	**Royal Children´s Hospital, Melbourne, Victoria**	**Alice Springs Hospital, Alice Springs, Northern Territory**	**John Hunter Hospital, Newcastle, New South Wales**
Check-ups	3 monthly, sometimes more often	3 monthly, sometimes every 6 weeks	3 or 6 monthly	3 monthly 2 monthly for toddlers

6.1.11 Education

Oslo University Hospital

The whole multidisciplinary team is responsible for educating the child with diabetes and his or her family. Group teaching is not practiced. The child´s doctor and the nurses in the team are the main responsible for the education, but the rest of the team is also involved in the education, from the time of diagnosis. A thorough education program is fulfilled in the period immediately after the child is diagnosed, based on the ISPAD guidelines. Further education is done at each check-up. In addition to educating the child and family, the diabetes nurses offer to visit the child´s school or nursery, soon after the child has been diagnosed, to educate the teachers or caretakers about diabetes. From third grade some basic diabetes education is also given the pupils in the child´s class.

Royal Children´s Hospital

Also at RCH the doctor(s) treating the child, and the diabetes team are responsible for educating the child and family. On request a psychologist and/or school nurse can get involved. At the time of diagnosis the family goes through an intensive education program with the diabetes educators and the dieticians. This happens individually as for the families at OUH. They also get advice and information from the paediatrician and the social worker. The family receive a lot of papers and information compendiums. After thorough education lessons the family and child complete a Diabetes Care Quiz. This is mainly to discover areas that are not explained well enough in the education sessions.

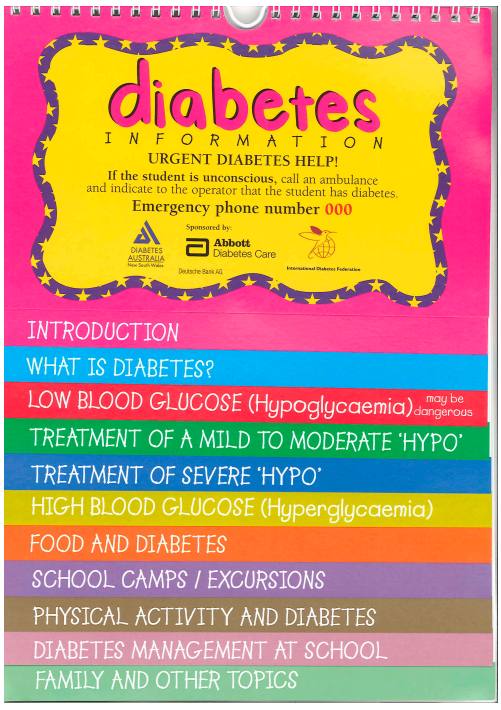
Schoolteachers and caretakers at nurseries are offered to come to school seminars arranged at RCH, to learn the basics about T1D in young people.

Alice Springs Hospital

At ASH the child and family are educated individually at the hospital in the first days following the diagnosis. The three important tasks the child and family must manage before they are discharged are blood glucose management, insulin injections and hypoglycaemia management. The teachers at the child´s school or nursery are educated through Healthy Living NT (Diabetes Australia).

John Hunter Hospital

All education is organised individually at JHH, not in groups with other families of children with diabetes. In addition to the child with newly diagnosed diabetes and the closest family, education is also offered grandparents, the nursery and school. Among other things the team try to arrange school visits, where the child´s teacher receives a school kit (Picture 1) with information on T1D in general and in association with the child. This task is both time and staff demanding, and although the team wish to accomplish this for all the children it has to target and prioritize the higher risk patients, e.g. toddlers on pump.



Picture 1: Information brochure from the school kit

6.1.12 Re-education

I witnessed the importance of re-education several times during clinical work on this thesis. Both children and parents easily forget and omit important tasks in the management of their condition. My impression is that the families manage the treatment of diabetes more appropriate when they are reminded once in a while what diabetes does to the child's body, how insulin works on the cells and why good glucose control is essential, not only to reduce the risks of late complications but also to optimize the daily quality of life.

Oslo University Hospital

At OUH all children with diabetes are invited to re-education when they turn 12 years. The re-education is organized in groups. In addition extra education is offered when the doctor, team or family assume this is appropriate.

Royal Children´s Hospital

At RCH re-education is not routinely coordinated. If families and children and their doctor or diabetes educators agree on the necessity of extra education sessions, this is easily organized through the diabetes team.

Alice Springs Hospital

The patients and their families managed at ASH, receive some kind of re-education at every check-up. Further organized re-education is arranged through Healthy Living NT (Diabetes Australia).

John Hunter Hospital

At JHH re-education is not arranged on a regular basis, but on a needs basis. The endocrinologists and the diabetes team wish re-education could become a regular part of the management of children with diabetes.

6.1.13 Family involvement

There is a fine balance between giving the child too much responsibility for his or her diabetes and being overprotective. How much the parents should be involved in the management of their child´s diabetes depends on a lot of factors, including the child´s age and personality trait.

Oslo University Hospital

At OUH, young children attend the diabetes appointments with their parents. As they grow older many patients choose to come alone. However, because the diabetes team wish to involve the parents as long as they are followed up at the children´s clinic, parents must come together with their child to at least one appointment every year. If a patient´s glycaemic control deteriorates the parents are always encouraged to get more involved and accompany their child to all appointments.

Royal Children´s Hospital

At RCH most often the parents accompany their child to all clinics. The allied health team at RCH are very aware of the how difficult it might be for the parents to know how much they should participate in their child´s diabetes management, and try their best to give the families ongoing guidance and advice. They often remind the families about the importance of trying to reduce the burden of the chronic illness for the child by giving as much support and help as the child needs at all times. For example, when their child goes through a major psychosocial event, e.g., a severe hypoglycemia or a DKA, it is useful to identify a responsible adult to prepare and inject insulin and do all blood glucose testing for a while until the child feels secure and ready to take over his or her treatment again.

Alice Springs Hospital

At ASH the parents accompany the children to check-ups.

John Hunter Hospital

At JHH the children also come with their parents to check-ups.

6.1.14 Focus on Quality of Life (QoL) in children with type 1 diabetes

There was limited information available on QoL and mental health problems among children with T1D followed up at the four visited hospitals. However, at OUH, RCH and JHH research is being conducted. One of ongoing studies at RCH focuses on the use of coping skills in diabetes education. At ASH no research on psychological issues has ever been conducted.

Oslo University Hospital

At OUH they have applied a counselling approach called motivational interview, a patient-centred method of engaging intrinsic motivation to change behaviour, in order to strengthen

the patient´s coping ability [105].

Social activities are not arranged by OUH. Nonetheless, Young Diabetes, which is a part of the Norwegian Diabetes Organization, offers courses, summer camps and other social activities on a national and a local level.

Royal Children´s Hospital

No social activities are arranged by RCH. However, all children with T1D and their families are encouraged to engage in Diabetes Australia Victoria, the Victorian branch of Diabetes Australia, and participate in meetings, extra education sessions, camps and other social activities that are arranged by this organization. Each year the organization arranges five camps for more than 200 children between four and 17 years with T1D. The goal at these camps is to teach young people to manage their diabetes in a fun, safe and supportive environment [106]. Doctors, the diabetes team, patients and parents have expressed how valuable and popular these camps are. Unfortunately, the waiting lists to attend diabetes camps are often long.

Alice Springs Hospital

ASH does not arrange camps, but the Healthy Living NT arranges camps and other social activities for patients with diabetes in NT. The organisation of these activities is much the same as for Diabetes Victoria.

John Hunter Hospital

Children and adolescents managed at JHH can attend Diabetes camps. They are arranged twice yearly by Diabetes Australia in NSW. One camp for children between nine and 12 years, and one for children between 13 and 18 years. Diabetes Australia in NSW also arrange other social activities like Diabetes Victoria and Healthy Living NT do.

6.1.15 Screening programs

All the hospitals have screening programs for autoimmune diseases associated with T1D (Table 11). The programs include screening for hypothyroidism, hyperthyroidism and celiac disease, and is performed at diagnosis and then annually or in the presence of clinical symptoms (RCH). In addition, at JHH they check for B12 deficiency.

Table 11: Screening for other autoimmune disorders in one hospital in Oslo, Norway and three hospitals in three different states in Australia

		Oslo University Hospital, Oslo	Royal Children´s Hospital, Melbourne, Victoria	Alice Springs Hospital, Alice Springs, Northern Territory	John Hunter Hospital, Newcastle, New South Wales
Screening for autoimmune diseases		At diagnosis, then annually	At diagnosis and if clinical symptoms of the diseases are detected	At diagnosis, then annually	At diagnosis, then annually
Diseases screened for	Celiac disease	x	x	x	x
	Hypo- and hyperthyroidism	x	x	x	x
	B12 deficiency				x

At OUH, RCH and JHH there are screening programs for some of the late complications associated with T1D. Unfortunately ASH does not have this. They check for complications when needed (Table 12). Furthermore, no screening is done for detection of psychosocial problems, at any of the hospitals.

Table 12: Screening for diabetes complications in one hospital in Oslo, Norway and three hospitals in three different states in Australia

	Oslo University Hospital, Oslo	Royal Children´s Hospital, Melbourne, Victoria	Alice Springs Hospital, Alice Springs, Northern Territory	John Hunter Hospital, Newcastle, New South Wales
Screening for microalbuminuria and nephropathy	Annually from 11 years of age after 2 years from diagnosis and annually from 9 years of age if 5 years from diagnosis (ISPAD guidelines)	Annually in adolescents after two years of diabetes and after five years of diabetes if prepubertal at diagnosis (APEG guidelines)	Checked when needed	Annually in adolescents after two years of diabetes and after five years of diabetes if prepubertal at diagnosis (APEG guidelines)

	Oslo University Hospital, Oslo	Royal Children´s Hospital, Melbourne, Victoria	Alice Springs Hospital, Alice Springs, Northern Territory	John Hunter Hospital, Newcastle, New South Wales
Screening for late retinopathy	Annually from 11 years of age after 2 years from diagnosis and annually from 9 years of age if 5 years from diagnosis (ISPAD guidelines)	Annually in adolescents after two years of diabetes and after five years of diabetes if prepubertal at diagnosis (APEG guidelines)	Checked when needed	Annually in adolescents after two years of diabetes and after five years of diabetes if prepubertal at diagnosis (APEG guidelines)
Screening for neuropathy	None	Yes, in risk patients. APEG guidelines: In the presence of poor diabetes control, clinical evaluation of peripheral nerve function should occur annually	Checked when needed	Yes, in risk patients. APEG guidelines: In the presence of poor diabetes control, clinical evaluation of peripheral nerve function should occur annually
Screening for hypertension	At diagnosis and annually	At diagnosis and, if normal, annually (APEG guidelines)	Checked when needed	At diagnosis and, if normal, annually (APEG guidelines)

6.2 Discussion

6.2.1 Type 1 diabetes - a complex and challenging disease

T1D is a complicated, serious and widespread chronic disease, associated with a lot of challenges physically, psychologically and socially, especially among children and adolescents. It is a disease that the patient has to live with - day and night - for the rest of his or her life. Keeping in mind how demanding T1D is for a young person, and also for the family, it becomes clear how crucial a highly qualified diabetes care team is. The patient and family need ongoing support concerning medical, social and psychological issues. Diabetes teams consisting of not only medical personnel, but also social workers, dieticians and mental health workers will together offer a more comprehensive diabetes care.

6.2.2 Organisation of the diabetes management

Both Australia and Norway have advanced diabetes care programmes, and most patients with T1D living here have access to optimal insulin treatment, multidisciplinary diabetes teams and strong diabetes organisations. Although the incidence and prevalence of T1D in children differed a great deal at the hospitals I visited in the three states in Australia and in the capitol of Norway (Table 5), the main principles behind the care and the guidelines that were adhered to, were quite similar. Nevertheless I observed a few important differences, especially when it comes to treatment regimens and how the follow-up activities were organized. This is described in the following 4 sub-chapters.

6.2.2.1 Treatment regimens

At OUH approximately 300 children and adolescents are followed up yearly, of which 62% are on the insulin pump. At RCH on the other hand care for approximately 1500 children with T1D and half of them are on a twice-daily insulin injection regime. At ASH approximately eight children with the same diagnosis are followed up, and all these patients are on the twice-daily insulin injection regime. At JHH, with a number of 360 young patients with T1D, multiple injection therapy is the most common regime (54%) (Table 7). However, less than half of the children and adolescents at all the four hospitals meet the ISPAD treatment goals (HbA1c < 7,5%), implicating that other factors than the insulin treatment regimens might be more important to focus on when trying to optimize the diabetes management.

6.2.2.2 Diabetes teams

Three of the hospitals (OUH, RCH and JHH) had multidisciplinary teams, but only one of these teams includes a psychologist (OUH). The teams are available at all times for the patients and their families (phone, email). At ASH the diabetes team lack both a social worker and a psychologist. However, an aboriginal liaison is engaged in the management of aboriginal children and families. All children diagnosed with T1D at ASH (and their families) receive one of the consultants private phone number at the time of diagnosis, thus help and support is always available.

6.2.2.3 Follow-up appointments

The frequency of the follow-up appointments was somewhat different at the visited hospitals. The three hospitals that had multidiciplinary teams as advocated in the ISPAD guidelines, also followed ISPAD´s recommendation concerning the frequency of the appointments (every

third month). However, at ASH some patients are seen more seldom (twice yearly), even though the paediatricians might wish to see them more often. One must keep in mind that many of the patients followed up at ASH have long distances to the hospital (up to several days of travel). Furthermore, social and cultural issues migh make it more challenging for some aboriginal patients to attend their appointments than for non-aboriginals. Fortunately, a diabetes educator from the state division of Diabetes Australia (Healthy Living NT) have close contact with the families and assist in the follow-up outside the hospital.

At RCH the check-ups are organised differently than at the other three hospitals. At OUH, ASH and JHH the patients with diabetes come to their out-patients appointments together with other children who have different diagnoses. At RCH all the children with T1D come to their check-ups on one of two designated afternoons every week (Diabetes clinics). In my opinion this system had several advantages. First of all, the whole team, including educators, social workers and dieticians, was available for the families when they waited for the appointment with their paediatrician. This made it easy for the families to ask for advice and book extra education sessions. One educator and one dietician also had appoinments with families on these days. In addition, I recognized how valuable it was both for the children and their parents to meet others in the same situation. Keeping in mind that the number of children with T1D is a lot higher at RCH than most other hospitals, the organisation of designated diabetes clinic days might be difficult to accomplish at hospitals with fewer T1D patients, and perhaps more importantly at hospitals with less resources.

6.2.2.4 Insufficient re-education

In my opinion none of the hospitals I visited had sufficient organised re-education. At OUH all children are re-educated once – at the age of 12. At RCH, ASH and JHH re-education is arranged solely on a needs basis. Perhaps, the diabetes teams should consider organising re-education on a more regular basis. I have seen how easily children and families forget what T1D really is, and how their diabetes control may deteriorate when it becomes unclear what causes hypo- or hyperglycaemias and why insulin is crucial. Implementation of organised re-education might help the patients and families to get a better understanding of the disease, thus cope better with it. It is important to remember that diabetes is a chronic and progressive disease and that the young patient´s needs continuously change as they meet the challenges associated with growth and development. Therefore, all forms of education and support must

be customized and relevant for the different ages and stages of the patient group, again emphasizing the value of re-education on a regular basis.

6.2.3 Coping with the diabetes

The diabetes care team have an important task in helping the children and their families to accept the diagnosis. Accepting one´s condition is essential. When participating in diabetes clinics, especially in the education sessions with newly diagnosed children, I recognised the importance of understanding what T1D is, accepting it and learning how to cope with it. When the patient copes well with his T1D he will feel that he is in control of the condition and that again might increase his QoL and glycaemic control. The patients should be taught coping skills from the time of diagnosis and these skills should be reassessed regularly, for example in re-education sessions. The training should be customized, taking into account the patients age, personality trait, social situation, resources etc.

6.2.4 The family´s role

Not only the patient must learn how to cope, so must the family. When a child is diagnosed with diabetes, the whole family receives a chronic diagnosis. How families cope varies greatly. Getting a child with a chronic disease is without doubt frightening and demanding. Some parents even develop anxiety and other mental health issues. Most of the responsibility for the care of children with diabetes rests with the family, thus when parents cope inadequately, this will consequently have negative impact on the child. Even in older children and adolescents who have taken over most of the responsibility for their treatment, the way the whole family cope is still essential. As the children grow older the parent´s role remains important, but must change from that of a parent to more of a coach [107]. This requires parents with a good understanding of the disease and with their own coping skills in place. Therefore early assessment of family dynamics is important, and help and support from the diabetes team have to be tailored to each individual family.

6.2.5 The relationship between quality of life and metabolic control

Achieving good quality of life and strict metabolic control is an enormous challenge for the patient, his or her family and the health care team. Childhood and adolescence is a time filled with critical changes associated with growth and development, both physically and psychologically, which makes it extraordinary challenging to handle a chronic diagnosis. Youth are vulnerable. Finding an identity is an important task in childhood and adolescence,

and every child and teenager wants to be normal, to be accepted and succeed at school, in sports and among friends. Diabetes interferes with these needs. It affects the young persons daily life and makes them feel different. Adolescents with T1D are the group of patients with the worst glycaemic control compared to other age groups [108, 109]. The growth and the hormonal changes in this period of life make optimal insulin treatment even more complicated. A reduced glycaemic control might lead to reduced quality of life and vice versa. Studies have shown that psychological treatment can slightly improve glycaemic control in young people with diabetes [83, 110]. This should draw attention to an increased focus on how to optimize the patients QoL. More research on coping skills, motivational enhancement therapy and cognitive behavioural therapy as tools in the diabetes treatment is required.

6.2.6 Strengthening in psychosocial support

Many children and adolescents with T1D report poor wellbeing. Furthermore, they are more prone to psychological disorders such as depressions and eating disorders than their peers. If children develop mental health problems in addition to their diabetes, this will necessarily reduce their quality of life, affect their glycaemic control and increase their risk of early diabetes complications.

Keeping in mind the fact that psychological problems might be one of the most important complications associated with diabetes in young patients, a strengthening in psychosocial support to the patients and their families should be proposed. The diabetes teams I met in Australia lack a psychologist, which is an acknowledged weakness. At JHH and at RCH they are working hard to get enough funding to employ a psychologist or psychiatrist. Even though OUH in Oslo has a psychologist on the team, this is just a part-time employment and the need of more psychological expertise is required.

6.2.6.1 Screening for psychological problems

At all the hospitals I visited screening for late complications is performed. OUH follow the ISPAD guidelines for screening of complications. RCH and JHH follow the APEG guidelines, which are quite similar (Table 12). However at ASH screening for complications is only done when the health professionals consider this necessary (Table 12). Moreover, all the four hospitals lack screening programs for psychological problems.

Increased focus on mental health and QoL should start at the time of diagnosis with mental health screening as part of the established diabetes complication screening program. Early detection and treatment of emotional problems might increase the patients QoL and thus perhaps their glycaemic control. It may also reduce the risk of developing more severe psychological problems.

6.3 Conclusion

Achieving both metabolic and psychological stability in children and adolescents with T1D requires a multidisciplinary diabetes team that is equipped to provide physical, social and psychological support. A psychologist should be a compulsory part of the diabetes team. Early psychological interventions, assessment of family dynamics, introduction to regular re-education and practice in coping skills, together with encouragement and optimism, are important factors in the complex organisation of diabetes care for young people.

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8 Appendix

Questionnaire – Type 1 diabetes in children

Universitetet i Oslo
Det medisinske fakultet

QUESTIONNAIRE – TYPE 1 DIABETES IN CHILDREN

THE QUESTIONNAIRE IS DESIGNED TO GATHER INFORMATION ABOUT CHILDREN WITH DIABETES ≤ 15 YEARS OF AGE. THE INTERVIEW WILL BE SPLIT IN TWO AND EACH ROUND SHOULD LAST A MAXIMUM OF 1 HOUR.

The first part of the interview is designed to map T1D in children at a national or regional level. Each country has a number code (see list). The regions/counties/states are indicated by names. The interviewer fills out this first part of the interview based on information available on the Internet and other places. She will then talk it thorough with the local informant.

The second part of the interview is designed to map T1D in children at the local hospital/treatment facility. The interview contains multiple qualitative questions; therefore the interview will be tape-recorded. The tape recordings will be transcribed before the analysis takes place.

The schemes do not contain personal sensitive information.

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PART 1

Country (code):
Region/county/state:
Date:
Informant: name/occupation:
Interview by:

Incidence

1. What is the annual incidence of the different types of diabetes in this country (enter the number and percentage)?
    - Type 1 diabetes
    - Type 2 diabetes
    - Gestational diabetes

2. What is the incidence of type 1 diabetes (T1D) among children under 15 years of age?

3. How is the distribution in the following groups of ages (estimated):
    - <5 years
    - 5-<10 years
    - 10-<15 years
    - > 15 years

4. Among children with T1D, what is the gender distribution?

5. What are the overall proportions of the following ethnicities in this country:
    - White / European background (non-Hispanic whites)
    - Black / African background
    - Middle-East / North-African
    - Indian subcontinent
    - East-Asia
    - Middle- and South American (Hispanics)
    - Indigenous (specify)
    - Mixed (or unclassified)

6. How many children with diabetes are
    - White / European background (non-Hispanic whites)
    - Black / African background
    - Middle-East / North-African
    - Indian subcontinent
    - East-Asia
    - Middle- and South American (Hispanics)
    - Indigenous (specify)
    - Mixed (or unclassified)

8.1 Prevalence

7. What is the total prevalence of T1D among children?

8. What is the prevalence of T1D among children in the following age groups?
    - <5 years:
    - 5-<10 years:
    - 10-<15 years:
    - ≥ 15 (adults):

Mortality

9. What is the average life expectancy in the country for women?

10. What is the average life expectancy in the country for men

11. What is the average life expectancy among female patients diagnosed with T1D before the age of 15?

12. What is the average life expectancy among male patients diagnosed with T1D before the age of 15?

National health

13. How many doctors per citizen?

14. Is there a geographical difference in availability of doctors?

15. What is the gross domestic product (GDP) of the county?

16. What is the total expenditure on health as a percentage of the GDP?

17. What is the general government expenditure on health as percentage of total expenditure on health?

18. What is the private sector expenditure on health as percentage of total expenditure on health?

19. What is the general government expenditure on health as percentage of general government expenditure?

20. Are there any support systems that finance the costs associated with diabetes medication and equipment?

21. If the answer is yes on question 20, which proportion of the following *medication* is financed
    - Insulin
    - Antidiabetic drugs
    - Glucagon

22. If yes on question 20, which of the following *materials* is financed?
    - Syringes:
    - Needles:
    - Insulin pen:
    - Insulin pump:
    - Materials for the insulin pump: (needle, catheter, reservoir..):
    - Home Blood Glucose meters:
    - Blood glucose test strips:
    - Finger-pricking devices:
    - Lancets for finger-pricking:
    - Continuous subcutaneous glucose monitoring devices:
    - Urine sticks to check for ketonuri:
    - Other:_____

23. If the answer is yes on question 20, does the patient have to pay anything? If so, how much? (%)

24. Who brings the child to their check-ups?
    - Mum
    - Dad
    - Other:_____ (specify)

25. Are there any laws/public rights for parents to get time off work to take their children to check ups?

26. Do parents with ill children get "sick-days"?

27. Do parents with chronic ill children get extra "sick-days"?
    - No = 0 days
    - 1-3 days
    - 4-6 days
    - 7-9 days
    - 10-12 days
    - 13-15 days

28. Are there national guidelines for the management of children with T1D?

Patient organizations

29. Are there any national organizations for patients with T1D?
    - For children
    - For children and adults
    - For adults only
    - No

30. Are there any local organizations for patients with T1D?
    - For children
    - For children and adults
    - For adults only
    - No

31. What do the patient organizations offer the children and their parents?
    - Websites
    - Telephone
    - Courses
    - Information meetings
    - Holiday offers
    - Other:_____

Register for diabetes

32. Is there a national diabetes register?
    - For children
    - For adults
    - For adults and children
    - No

33. If yes on question 32, what data is registered?
    - Incidence
    - Acute complications
    - Late complications
    - Other:

Complications

34. What is the incidence of acute diabetes complications among children under 15 years of age?
    - Diabetic ketoacidosis (with hospitalization)
    - Grave hypoglycemia (unconscious with or without convulsions)

35. What is the incidence of late diabetes complications among children under 15 years of age? (estimated percentage)
    - Retinopathy
    - Nephropathy
    - Neuropathy

Country (code):
Region/county/state:
Date:
Informant: name/occupation:
Interview by:

PART 2

Hospitalizations and number of hospital beds

36. How many children <15 years with T1D are admitted to hospital annually in the following wards (The total number of hospitalizations including rehospitalization)
    - Children ward
    - Adolescents ward
    - Internal medical ward

37. How long are the children managed in the pediatric department? (up to what age)

38. Is there an adolescent department?

39. If yes on question 38, which group of age attend to the adolescent department?

40. What is the maximum number of beds in the ward?

41. How often has the ward been full during the last 6 months? (regardless of the reason for the hospitalisation)

42. How many children with T1D are followed up at the local hospital today?

43. How is the gender distribution among the children that are followed up at the local hospital?

Diagnostics

44. Who usually make the diagnosis?
    - General practice
    - Specialised health service
    - Nurse
    - Other:_____

45. What is the average age at diagnosis?

46. What are the classical symptoms that make the patient and his or her parents contact a doctor?

47. Which diagnostic criteria have to be fulfilled to make the diagnose T1D?
    - International guidelines
    - ADA
    - Other

48. Where are recently diagnosed juvenile diabetics treated the first time?
    - Out-patients clinic
    - Hospital ward with beds

49. If the patient is admitted to hospital, what is the average length of stay?

50. Which diagnostic criteria do you use for DKA?
    - Hyperglycemia
    - Standard Bicarbonate (< 15 mmol)
    - pH (< 7,3)
    - Urine ketons

51. What proportion of children has DKA at diagnosis? Treatment and follow up

52. Who participates in the treatment and follow up of children with T1D?
    - Nurse
    - Doctor
    - School nurse
    - Social worker
    - Nutritionist
    - Psychologist
    - Other
    - Multidisciplinary team

53. Does the child with T1D have one particular contact person? If yes, specify:

54. When the diagnosis is made who is responsible for the follow-up?
    - Specialist (endocrinology)
    - Hospital doctor
    - Nurse
    - General practitioner
    - Other:_____

55. Who are educated (at the time of the diagnosis, and after discharge)?
    - The child
    - Parents
    - School
    - School nurse
    - Nursery

- Activity leaders/coaches
- Others:
- No one

56. Does the hospital have access to interpreters when they have patients that do not speak/understand English?

57. How is the education organized?
    - Training in groups
    - Individual training
    - A combination of both

58. Do you organize re-education?

59. At what age is the re-education organized?

60. How is the reeducation organized?
    - Training in groups
    - Individual training
    - A combination of both

61. How do parents participate in the treatment and follow up?

62. Is carbohydrate counting used systematically when calculating the insulin bolus in relation to food? Yes

63. Do the adolescents get contraceptive counseling

64. Have you experienced unintended pregnancies in this group of patients

65. What are the characteristics of these patients? (ethnicity, socioeconomic status etc)

66. What types of treatment/treatment regimens are available for children with T1D at the local hospital?
    - Syringes
    - Needles
    - Insulin pen
    - Insulin
    - Continuous Subcutaneous Glucose Monitoring
    - Others

67. How many patients use multi injection (insulin > 3 times a day) therapy?

68. What proportion of the patients (in percentage) follow the different treatment regimens listed
    - Insulin
    - Multiinjection therapy without pump
    - Injections less than 4 times a day

- Others

69. Among the children under multi injection therapy what type of insulin preparations are used? (%)
    - Premixed insulin preparations
    - Intermediate-acting insulin + rapid-acting insulin
    - Analogues (Comment: Which combinations: _____)

70. With sight to multi injection therapy are there any different strategies for insulin therapy concerning the child's age?

71. Who does the patient and his or her parents contact if the child is acute ill?
    - Specialist
    - Contact person
    - General practitioner (GP)
    - Emergency room
    - Other

Treatment goals

72. Are the ISPAD treatment goals adhered to?

73. If no, are other guidelines followed?

74. What are the treatment goals
    - $HbA1_c < 7,5$ %
    - Other

75. What proportions (%) of patients achieve the treatment goals?

76. How often do the children attend diabetes health check ups?

77. What proportions of the patients attend their appointment?

78. What are the characteristics of the patients who not attend to their appointment?

79. Is there a screening program for autoimmune diseases?

80. If yes on question 79, which diseases are included in the screening
    - Celiac disease
    - Hypothyroidism / hyperthyroidism
    - Others

81. If yes on question 79, how often is the screening performed
    - At each check up
    - Annually
    - Other

82. Are there any screening program concerning late diabetes complications among children with diabetes?

83. If yes on question 82, what kind of late diabetes complications are included in the screening program among children with diabetes? Specify which methods are used in the screening.
    - Retinopathy
    - Nephropathy
    - Neuropathy
    - Others

84. If yes on question 82, how often is the screening performed
    - At every check up:
    - Annually:
    - Other

Quality of life and mental health:

85. What assistance do the children with T1D and their parents receive in relation to school, hobbies and sports?

86. Are there social activities arranged for the children and their parents?

87. What kind of social activities are arranged? And who organises them?

88. Have you conducted/do you conduct research on the quality of life in the children with diabetes?

89. Are drug or alcohol abuses a problem among children with T1D?

90. If yes on question 90, what kind of abuse? (Alcohol, drugs, medications)

91. If yes on question 90 what are the characteristics of these patients? (gender, ethnicity, socioeconomic status etc)

92. What is the proportion (percentage) of acute diabetes complications among children with T1D under the age of 15?
    - Diabetic ketoacidosis
    - Hypoglycemic shock with unconsciousness and/or convulsions
    - Other

93. What is the proportion (%) of long-term complications among children under the age of 15 years? And how old are they?
    - Retinopathy:

    How many have been treated with laser?
    - Nephropathy:
    - Neuropathy:

- Hypertension

How many get anti hypertension treatment?

94. What is the proportion (%) of long-term complication among adults who got the diagnose T1D before they turned 15 years?

(The following must be discussed: How old were the patients when they where diagnosed with T1D? How many years diabetes duration at onset of the late complication?)

95. Is overweight a problem among children with T1D?
If yes:
    - Are there any differences between gender, ethnicity, socioeconomic background etc?
    - In which group is the prevalence of overweight highest?
    - What kind of prevention and treatment regimens does the hospital have?
    - Are the treatment regimens effective?
    - Do children with overweight in practice have significant more complications than children with normal weight?
    - Are there other problems related to overweight and T1D?